

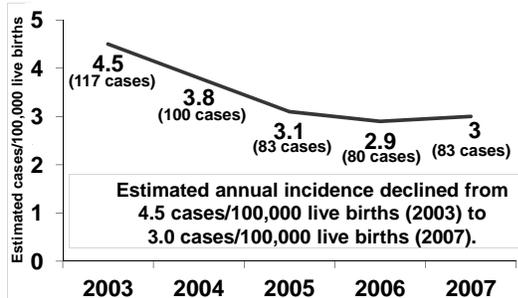
Eliminating Mother-to-Child HIV Transmission in the United States: The Role of the FIMR-HIV Prevention Methodology

Produced by the Alabama Department of Public Health
Video Communications and Distance Learning Division

Faculty

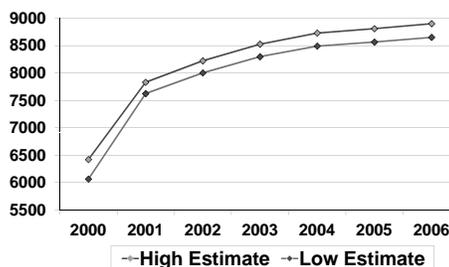
Steven Neisheim, MD
Centers for Disease Control
and Prevention

Estimated Annual Incidence of Perinatal HIV Infection, 33 States, HARS, 2003-2007 (N=463)



Taylor, et al. 6th IAS Conference, Rome. July 18, 2011

Estimated Number of Births to Women Living with HIV Infection, 2000-2006



2006 estimate (8,650 – 8900) is ~30% > 2000 estimate (6075 – 6422)
Office of Inspector General (Fleming), 2002 Whitmore, et al. CROI, 2009

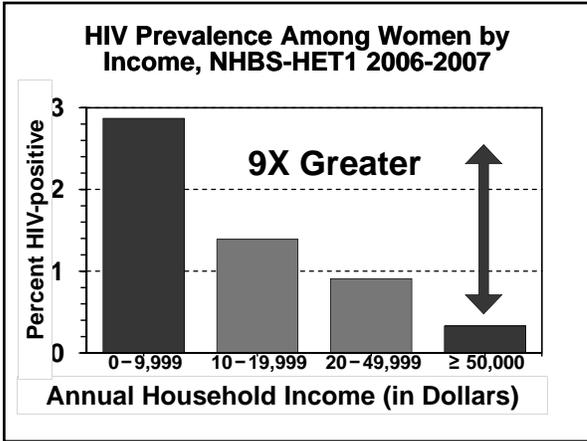
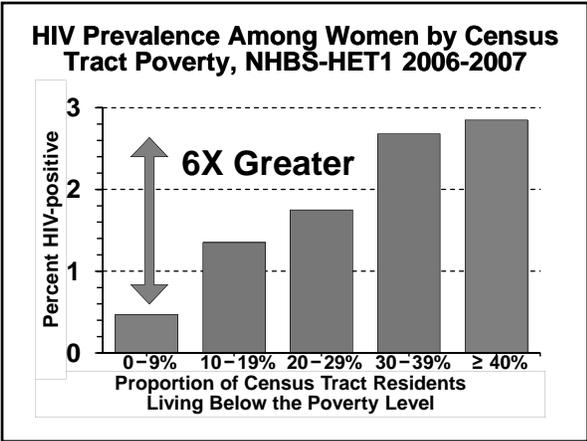
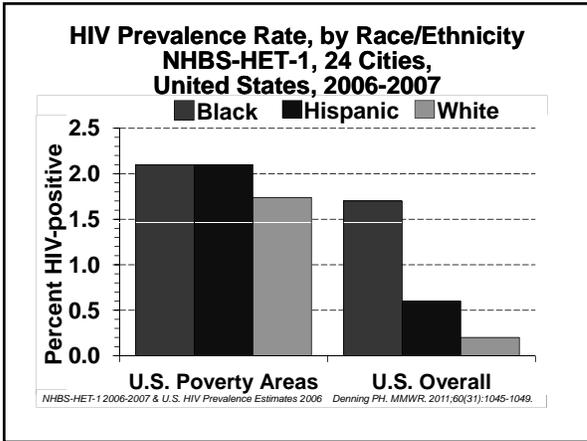
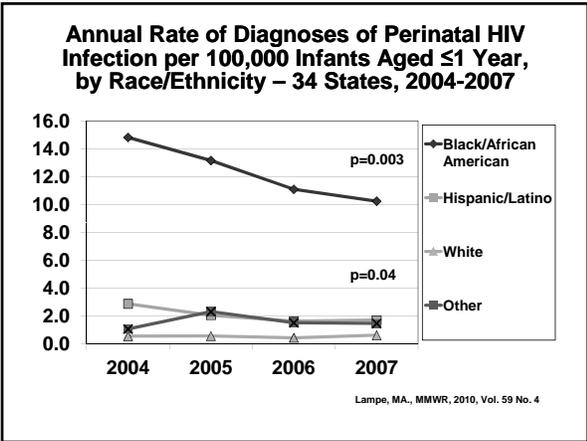
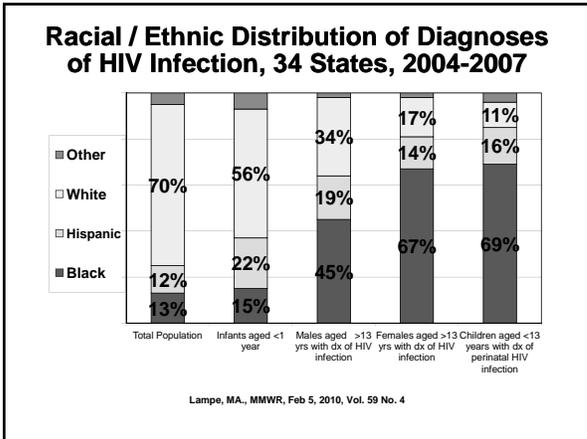
Elimination of Mother-to-Child HIV Transmission (EMCT) Goal

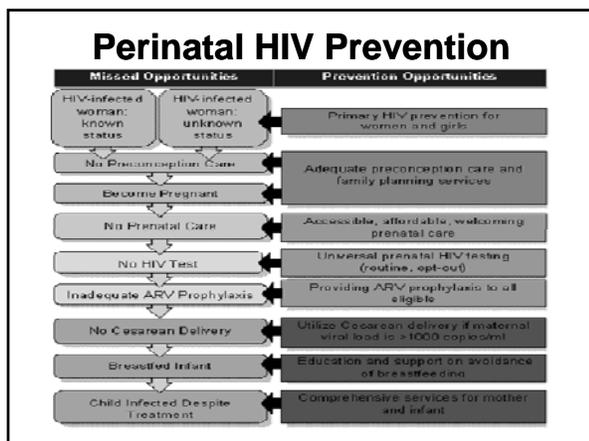
- MCT incidence < 1 per 100,000 live births
 - <40 cases among an annual cohort of 4 million births
- Transmission rate < 1%
 - <87 cases in 2006 (8,700 HIV-exposed births)

Elimination of Mother-to-Child HIV Transmission (EMCT) Goal

- Each of these goals represents a reduction of approximately 100 cases per year

**Where Are We Now
in Terms of the EMCT Goal?**





HARS, Diagnoses of Perinatal HIV Infection, 33 States, 2003-2007

- Missed prevention opportunities
 - Common missed prevention opportunities
 - Lack of prenatal care
 - 62% had ≥ 1 visit

HARS, Diagnoses of Perinatal HIV Infection, 33 States, 2003-2007

- Late maternal diagnosis
 - 26.6% diagnosed after birth
- Lack of antiretroviral medications
 - 28.7% received prenatal ARV
- Breastfed
 - 12.4%

HARS, Diagnoses of Perinatal HIV Infection, 33 States, 2003-2007

- We don't know how and why these occur at the local level
- Likely dependent on local systems issues

– Taylor, et al. 6th IAS Conference, Rome, July 18, 2011

HARS, Diagnoses of Perinatal HIV Infection, 33 States, 2003-2007

- Geographic distribution
 - Five states (FL, NY, TX, LA, NJ) accounted for 57% of diagnoses reported from the 33 states and 5 dependent areas

HARS, Diagnoses of Perinatal HIV Infection, 33 States, 2003-2007

- Region of the United States
 - South 54 % (3 of top 5 states)
 - Northeast 21%
 - Midwest 14%
 - West 8%

HARS, Diagnoses of Perinatal HIV Infection, 33 States, 2003-2007

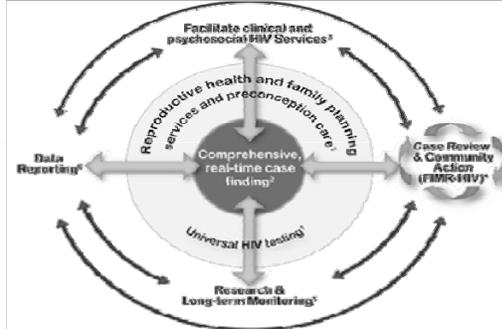
- A few with many cases
- Many with a few cases
- None with no cases
- Important to maintain some capacity even in low-incidence areas

HARS, Diagnoses of Perinatal HIV Infection, 33 States, 2003-2007

- Data not available for many high-burden areas: CA, CT, DC, DE, GA, IL, MA, MD, others

- Taylor, et al. 6th IAS Conference, Rome, July 18, 2011

Framework to Eliminate Mother-to-Child HIV Transmission in the United States

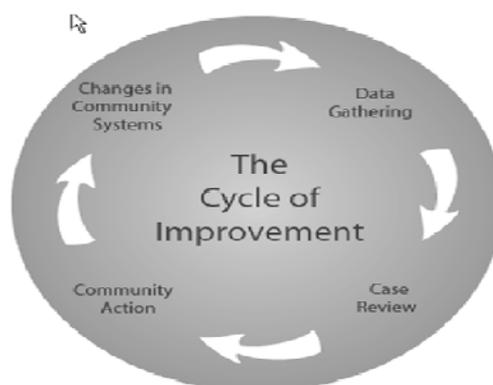


National HIV/AIDS Strategy Goals July, 2010

- Reduce HIV incidence
- Increase access to care and optimize health outcomes
- Reduce HIV-related health disparities
- Achieve a more coordinated national response

Overview of FIMR – HIV: Continuous Quality Improvement

- Case Identification
- Data Abstraction
- Maternal Interview
- Case Review
- Community Action



Overview of FIMR – HIV

- **Case identification and selection**
- **Case definition**
 - HIV-exposed infant/fetus \geq 24 weeks gestation, <24 months old
- **Purposeful, not random selection, based on an indication of system gap:**
 - HIV-infected infant

Overview of FIMR – HIV

- Late maternal HIV diagnosis
- Lack of, or inadequate prenatal care
- Lack of maternal treatment or poor viral suppression
- Lack of antiretroviral prophylaxis during labor and delivery

Overview of FIMR – HIV

- **Data abstraction**
 - All available medical, hospital, CM records

Overview of FIMR – HIV

- **Information collected:**
 - Prenatal care, labor and delivery care, post-partum/reproductive health care, maternal HIV care, newborn care, birth certificate and general pediatric care and pediatric HIV care
- De-identified (case and health care setting)

Overview of FIMR – HIV

- **Maternal interview**
 - Critical to the process
 - Information not available in the medical record
 - Obtain the woman's unique perspective

Case Review

- **Multidisciplinary case review team**
 - MCH, HIV/AIDS, community, advocates, professional organizations, private agencies, HIV experts
 - Review Cases
 - Sentinel Events
 - Trends

Case Review

- Incidental Findings
- Develop Initial Recommendations

Role of the Community Action Team

- Composed of those who have the political will and fiscal resources to create large scale systems change
 - Include a broad-based, multi-partner range of agencies and people (e.g. families, CBOs, consumer advocates, etc.) that represent the diverse ethnic and cultural groups in the community

Role of the Community Action Team

- Inclusive of HIV and MCH expertise
- Take CRT recommendations to ACTION
 - Creative solutions to improve services and resources
 - Prioritize and implement interventions

FIMR and FIMR – HIV Key Points

- Confidentiality is key
 - FIMR cases are de-identified

FIMR and FIMR – HIV Key Points

- FIMR-HIV focuses on systems
 - Opportunity to improve communication among medical, public health and human service providers and develop strategies to improve services and resources for women, children, and families

FIMR and FIMR – HIV Key Points

- FIMR-HIV includes a family perspective
 - A home interview with the mother is part of the methodology

FIMR and FIMR – HIV Key Points

- FIMR-HIV promotes broad community participation
 - FIMR is a community coalition that can represent all ethnic and cultural community views and becomes a model of respect and understanding

FIMR and FIMR – HIV Key Points

- FIMR-HIV is action-oriented
 - FIMR leads to multiple creative community actions to improve resources and service systems for women, infants, and families

Initial Work of FIMR – HIV

- 2005 – 2006
 - Adaptation of FIMR tools
 - Protocol development
- October 2005 – September 2008
 - RFA announced 3 pilot sites selected to work collaboratively with national partners to implement and refine methodology

Initial Work of FIMR – HIV

- September 2008 – October 2009
 - Development of resource center
 - Report from pilot published
 - Expansion of methodology to additional sites through an RFA process

Initial Work of FIMR – HIV

- Minimal funding
 - ~ \$20K per site to 7 sites
 - 2 sites participated without funding

FIMR/HIV Pilot Project Overview and Lessons Learned

Available at: www.fimrhiv.org

FIMR – HIV Sites

- FHPM Implementing Sites
 - Baltimore, MD
 - Broward County, FL
 - Chester, PA
 - Indianapolis, IN
 - New Orleans, LA
 - Newark, NJ

FIMR – HIV Sites

- Philadelphia, PA
- Washington, D.C.
- State of Illinois
- State of Michigan

FIMR – HIV Sites

- Pilot Sites
 - Detroit, MI
 - Jacksonville, FL
 - Baton Rouge, LA

Year 1 Highlights: New sites (Oct 2009 – Sept 2010)

- Start up time was intensive (4-12 months)
- IRB Process
 - Exempt IRB review = 4 sites and CDC
 - Expedited IRB review = 3 sites
 - 2 IRB reviews = 2 sites

Year 1 Highlights: New sites (Oct 2009 – Sept 2010)

- Train data abstractor and maternal interviewer
- Establish case ID process
- Stand up Case Review Team

Year 1 Highlights: New sites (Oct 2009 – Sept 2010)

Site	# Cases Reviewed	# Maternal Interviews
Baltimore, MD	10	9
Broward County, FL	18	10
Chester, PA	16	8
Indianapolis, IN	13	10
New Orleans, LA	15	5
Newark, NJ	0	0
Philadelphia, PA	3	3
Washington, D.C.	1	0
State of Illinois	15	8
TOTAL	91	53

Year 2 Highlights: New Sites (Oct 2009 – Sept 2010)

- Cases abstracted and/or reviewed: 112
- Maternal interviews completed: 54
- CRT meetings: 45
- CAT meetings: 13

FIMR – HIV Prevention Methodology Sites

- Recommendations
 - Universal across sites: improvements needed in family planning services
 - Improve Emergency Department services
 - Women lost to care

FIMR – HIV Prevention Methodology Sites

- Recommendations
 - Universal across sites: improvements needed in family planning services
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 - Women lost to care

FIMR – HIV Prevention Methodology Sites

- Improve support for formula feeding
- Actions/outcomes
 - Improved gaps in Medicaid
 - 2-week gap in infant meds
 - Improve linkages for HIV+ mothers of infants in foster care

FIMR – HIV Prevention Methodology Sites

- Decreased number of infants with indeterminate status in HIV surveillance
- Health Department successfully funded for Title X grant to increase testing, integrate HIV and FP services

FIMR – HIV Prevention Methodology Sites

- Ryan White Part A Assessment and Screening revisions to integrate HIV and reproductive health care

FIMR-HIV Prevention Methodology National Resource Center

- Training
- Facilitate collaboration with MCH and existing FIMR projects
- Conduct TA site visits
 - As resources permit

FIMR-HIV Prevention Methodology National Resource Center

- Create and facilitate a learning network of FIMR-HIV programs
- Other TA requests

FIMR/HIV Prevention Methodology National Resource Center

www.fimrhiv.org

FIMR-HIV Data System

FOA 12-1201 MCT (Perinatal) Activities

- Category A, Comprehensive Prevention with Positives
 - Conduct sentinel event case review and community action to address local systems issues that lead to missed perinatal HIV prevention opportunities

FOA 12-1201 MCT (Perinatal) Activities

- Utilize the Fetal and Infant Mortality Review (FIMR)-HIV Prevention Methodology
- CDC's web-based data system, www.fimrhiv.org
- Where appropriate and based on local need and the availability of resources

FOA 12-1201 MCT (Perinatal) Activities

- Technical assistance (TA) and data support may be provided by CDC and the FIMR/HIV National Resource Center

FOA 12-1201 MCT (Perinatal) Activities

- Category A, HIV Testing
 - Promote routine, early HIV screening for all pregnant women, according to current CDC recommendations

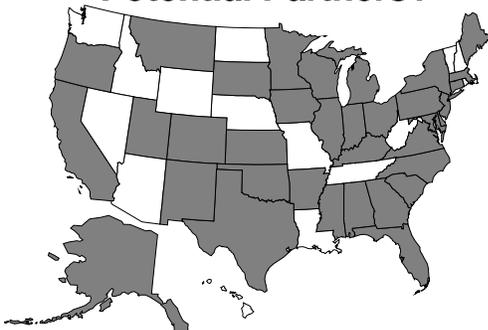
FOA 12-1201 MCT (Perinatal) Activities

- Category A, Comprehensive Prevention with Positives
 - Assure HIV-positive pregnant women receive necessary interventions and treatment for prevention of perinatal transmission (according to Perinatal ARV Guidelines, aidsinfo.gov)

FOA 12-1201 MCT (Perinatal) Activities

- Most HIV-infected pregnant women are in care
 - It will not be possible, and may not be necessary, for prevention programs to actively monitor each woman, once it has been determined that the woman is in care

220 FIMR Sites in 40 States: Potential Partners?



Moving Forward

- Training held June 7, 2012
- FOA announced for FIMR-HIV National Resource Center
 - 5 year project period
- Distance learning and technical assistance
- Exploring expansion to include congenital syphilis perinatal Hepatitis B